



STEVEN L. BESHEAR
GOVERNOR

**CABINET FOR HEALTH AND FAMILY SERVICES
DEPARTMENT FOR BEHAVIORAL HEALTH,
DEVELOPMENTAL AND INTELLECTUAL
DISABILITIES**

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Audrey Tayse Haynes
SECRETARY

TO: Audrey Tayse Haynes
Secretary

FROM: Betsy Dunnigan *Betsy D.*
Acting Commissioner

DATE: October 1, 2013

SUBJECT: Annual Status Report—HB 144 Commission

Attached for your review and signature is a letter to the Governor and General Assembly forwarding the tenth Annual Status Report of the Commission on Services and Supports for Individuals with Intellectual Disability and Other Developmental Disabilities, which is mandated by KRS 210.577(3), and is due on October 1.

Thank you for your consideration of this report.



**CABINET FOR HEALTH AND FAMILY SERVICES
OFFICE OF THE SECRETARY**

Steven L. Beshear
Governor

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Audrey Tayse Haynes
Secretary

October 25, 2013

The Honorable Steven Beshear
Governor
Commonwealth of Kentucky
700 Capitol Avenue, Suite 100
Frankfort, KY 40601

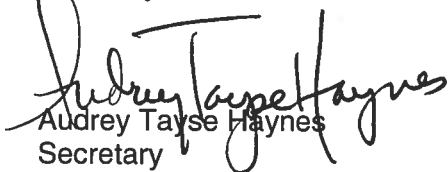
Dear Governor Beshear:

The Commission on Services and Supports for Individuals with Intellectual Disability and Other Developmental Disabilities is pleased to present you with the Eleventh Annual Status Report, submitted in accordance with KRS 210.577(3).

On behalf of the Commission, I want to thank you for your continued support of our work and your positive response to the needs of people with intellectual and other developmental disabilities.

You are invited to contact me if you have any questions about this report. I, along with other members of the Commission, would welcome the opportunity to discuss the Commission's work.

Sincerely,


Audrey Tayse Haynes
Secretary



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Audrey Tayse Haynes
Secretary

October 25, 2013

Ms. Marcia Seiler
Acting Director Legislative Research Commission
700 Capitol Avenue, Room 300
Frankfort, Kentucky 40601

Dear Ms. Seiler:

The Commission on Services and Supports for Individuals with Intellectual Disability and Other Developmental Disabilities is pleased to present you with the Tenth Annual Status Report, submitted in accordance with KRS 210.577(3). Please share this report with the members of the General Assembly as needed.

On behalf of the Commission, I want to thank you for your continued support of our work and your positive response to the needs of people with intellectual and other developmental disabilities.

You are invited to contact me, if you have any questions about this report. I, along with other members of the Commission would welcome the opportunity to discuss the Commission's work.

Sincerely,


Audrey Tayse Haynes
Secretary

ANNUAL STATUS REPORT



The Commission on Services and Supports for
Individuals with Intellectual Disability and Other
Developmental Disabilities

Submitted in Accordance with KRS 210.577 to:

Governor Steven L. Beshear
and the General Assembly
October 1, 2013



INTRODUCTION

The Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities was created and established by KRS 210.575 through the enactment of House Bill 144 by the 2000 General Assembly. The Commission serves in an advisory capacity to the Governor and the General Assembly about a variety of short and long-term initiatives that impact the lives of people with intellectual and developmental disabilities.

The Commission's current membership includes 29 individuals, 12 of whom are appointed by the Governor. These individuals represent family members, legislators, provider organizations, advocacy groups, and leaders from various state agencies. This year, nine of the 12 appointees' terms expired and new members were appointed by the Governor.

During FY 2012, the Commission formed three committees to address data reported through the National Core Indicator (NCI) project. Kentucky has participated in this nationwide project since 1999. The NCI survey provides a variety of data that is reported by people with intellectual and developmental disabilities, family members, and caregivers about the quality of their services and supports. An NCI Quality Improvement Committee was established to analyze the data, and it provided the Commission with information that has helped to identify priority areas: Health and Wellness, Participant Directed Supports, and Community Integration

FY 2013 PROGRESS

In 2012 Commission members, in collaboration with the Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID), established long-term initiatives for the next 5-10 years.

Summary of progress towards long-term initiatives during FY 2013:

- Community education and outreach must be a combined effort to create an awareness of need and available services for people with intellectual and developmental disabilities (I/DD).

Status Update: Community Integration Committee and DBHDID hosted three public forums across the Commonwealth with 75 attendees. The purpose of these and future forums is to identify the barriers to living in the community and gather information on how people choose to live and become a part of their community. The forums are also to identify potential solutions that can be utilized to improve the service system across the state. The forums were open to individuals, advocates, and family members who desired to comment on any aspect of the I/DD service system.

- Promote inclusion of citizens with disabilities to increase natural supports in the community and in the workplace.

Status Update: DBHDID continues to support services to encourage person centered supports, training, and education. *Community Belonging* is a program focusing on communities and community agencies becoming more person-centered. There will be an event hosted by DBHDID in October 2013 to celebrate the conclusion of Year 1 of the *Community Belonging* initiative which began in September 2012 under the guidance of Dr. Angela Amado from the University of Minnesota. Fifty individuals from 14 Supports for Community Living (SCL) agencies across the state signed up to participate in this program designed to assist individuals in developing friendships and becoming an active part of their community. Over the course of a year, the individuals, agencies, families, guardians, friends, and DBHDID staff have come together in 3 face-to-face trainings. In between face-to-face sessions, each agency, along with the individual's Team, has participated in agency specific webinars on 3 occasions with Dr. Amado and DBHDID staff to continue progress toward meeting goals set by the individuals at the start of the project.

Status Update: DBHDID has developed an action plan to promote the expansion of customized and self-employment for individuals that includes the following elements:

- Continue to expand the capacity of Kentucky's supported employment system for people with intellectual and other developmental disabilities with well-prepared providers who are committed to offering high quality supports;
- Educate individuals and family members about the benefits of employment through education and open forums;
- Motivate employers to hire jobseekers with I/DD; and
Improve coordination and implementation of policies as they relate to jobseekers with disabilities throughout the Commonwealth.

Status Update: In collaboration with DDID and the Office of Vocational Rehabilitation, the department has redesigned the required training for supported employment providers starting this fall. We will again offer our Supported Employment Leadership Training series this year.

- Advocate for adequate funding for a system of services and supports throughout the individual's lifespan.

Status Update: The Commission advocated for additional SCL waiver allocations. The legislature approved 600 slots over the FY 2013-14 biennium, which allowed 216 people in the Urgent category of the SCL waiting list to receive funding, and 376 people who met emergency criteria to receive funding.

- People with disabilities and their families will have continued access to services and supports that meet their needs and expectation.

Status Update: DBHDID is focusing on continuity of care in an effort to improve both access to and quality of supports. It has assigned field staff to each state Intermediate

Care Facility (ICF) and psychiatric hospital to provide technical assistance and to promote networking among the entities for successful transition to community based supports. DBHDID continues to work with the 14 Regional Community Mental Health Centers (CMHCs) to improve the quality of Crisis Services available to all adults with I/DD in the Commonwealth. Within the FY 2014 contract between DBHDID and the CMHCs there are two new initiatives regarding DD Crisis Services:

1. Completion of a Regional Inventory of I/DD Behavioral Health Needs by the Community Mental Health Centers; and
2. The development of a Quality Assurance Plan based upon review of 2011 and 2012 regional crisis contact data.

Additionally, all provider staff are now required to complete training in DBHDID's Crisis Prevention and Intervention curriculum which is based on best practices and includes Michael Smull's work on person-centered supports.

Status Update: The SCL waiver was revised and approved to include *community access* as a new service. This service is intended to encourage people with disabilities to engage in community life with others who share similar interests. This will also provide opportunities to empower and expand people's resources and enjoy a variety of health and wellness offerings in communities around the Commonwealth. The SCL waiver was also revised to increase supported employment rates by nearly 100% in an effort to offer more opportunity for people to get jobs and enjoy being a part of their community.

- The primary focus for public intermediate care facilities will shift to expand networks providing continuum of health care within the individual's community.

Status Update: As individuals transition from facility to community supports, the state ICF's continue to focus on becoming Centers of Excellence to serve as a resource to, and increase capacity of, the community.

Status Update: DBHDID partnered with the Department for Medicaid Services to submit an amendment to the Medicaid State Plan requesting approval from the Center for Medicare and Medicaid Services for specialty clinics providing medical, dental and therapeutic services for individuals with intellectual and developmental disabilities residing in the community. The departments received CMS approval for the state plan amendment and regulations have been filed.

Summary of progress of the HB 144 Committees during FY2013:

In FY 2013 each of the HB 144 committees were asked to focus on short-term goals to improve services for people with intellectual and other developmental disabilities.

Health and Wellness Committee

The National Core Indicators (NCI) data indicate that 21% of Kentuckians with I/DD engaged in moderate physical activity for 30 minutes a day at least three times a week, which is below the national average of 26%.

The breakdown by setting was:

18% for KY vs. national average of 26% in Community-Based Settings

28% for KY vs. national average of 29% in Individual Homes

25% for KY vs. national average of 28% in Parent's Homes

- **Goal:** Increase the overall percentage of SCL recipients who engage in moderate physical activity for 30 minutes a day at least three times a week by 5%, as reported in the next NCI 12 month data cycle.

Activity: A webinar for 210 SCL providers in August announced the “Health Messages” pilot project for up to 25 organizations, a collaborative effort with University of Illinois at Chicago’s Rehabilitation Research and Training Center on Aging and Developmental Disabilities. This 12-week program, introduced in October 2012, is led by an individual receiving supports who is teamed with a direct support professional. Results were used to launch a collaborative effort with the Human Development Institute at the University of Kentucky (UK) and the University of Illinois-Chicago for pilot projects around an evidence based health and wellness curriculum and a pilot self-advocate led program at 14 provider agencies, impacting over 100 individuals on the SCL waiver.

Activity: A survey was sent to SCL agencies asking the managers to respond regarding health and wellness of the people they support. Statistics included percentages of individuals with I/DD who are overweight and obese and the percentages of individuals who engaged in 30 minutes of moderate activity. It also compared those living in community based settings, individual homes, and parent’s homes.

- The survey sent to all SCL providers garnered 138 responses;
- Response rate of 54.1% - indicating tremendous interest in this area;
- Of all SCL agency responses, 23.3% do not offer Health/Wellness Programs;
- 23.3% offer 1-2 Health/Wellness Programs;
- 5.3% offer 3-4 Health/Wellness Programs; and
- 48.1% offer ongoing Health/Wellness Programs.

Activity: Along with the DBHDID, the Office of Vocational Rehabilitation, and the Department of Education, we are developing a series of webinars are being developed on transition for students with intellectual and developmental disabilities that will include: 1) the role of each agency in creating a person-centered transition plan and the necessary supports for it to happen:

2) evidence-based practices in transition; and 3) illustrative student and young adult examples of successful transitions. The webinars will be offered to high school special education teachers who work with students with significant disabilities, OVR counselors, and case managers who support individuals on the SCL and Michelle P Waivers. A “condensed” version of this training for parents, self-advocates, and other interested professionals will be offered as part of the HDI Fall Seminar Series on Friday November 18, 2013 from 1 to 3 PM, which will be video-conferenced to sites throughout the state.

Recommendations: The Health and Wellness Subcommittee offered the following recommendations to the Commission and DBHDID.

- Any significant initiative to improve health and wellness for Kentuckians with intellectual and developmental disabilities will require an investment in resources. At a minimum, the department needs to designate a dedicated individual to coordinate health and wellness initiatives with providers, other organizational partners invested in the health and well-being of individuals with developmental disabilities, and, to the extent feasible, with consumers and families. It is recommended that the department establish as official policy that all individuals receiving waiver services in collaboration with their person-centered teams consider a specific goal directed towards health and wellness on their Individualized Plan of Care.
- As survey data from SCL providers have indicated, any initiative to address health and wellness for individuals receiving services must also target Direct Support Professionals. It is recommended that training of Case Managers occur to ensure that Plans of Care reflect the health and wellness of the individuals served. This is especially important as the transition to Conflict-Free Case Management occurs.
- The provider survey found some very promising practices. It is recommended that the department ensure these are disseminated to providers through the Division of Developmental and Intellectual Disabilities (DIDD) webinars and other vehicles. For example, one agency works with its local UK Cooperative Extension Service to provide a Health and Nutrition Program to their clients, another works with the Horticulture Department of Murray State University on growing fresh fruits and vegetables, and a third uses local Farmers Markets to purchase foods.
- It is also recommended that a compilation of promising practices for providers also include the use of new services under the waiver to enable consumers to actively participate in their communities by purchasing their foods at local groceries, farmers markets, etc. Not only would this constitute an important experience in learning about health and nutrition, it would assist providers in connecting the individuals they serve to the life of their local communities.

Participant Direction

The Participant Directed Services (PDS) committee met regularly throughout the year. In order to have input from other resources regarding self-direction, the committee was expanded to

include representation from the Department of Education, Division of Learning Services, a parent of a youth in school who would be transitioning to the community, and other community members.

The initial meeting included an overview of the Mission, Vision, and Values of DBHDID. The committee was provided a copy of the National Core Indicator report that shows where Kentucky is ranked nationally. After reviewing this information, the committee was charged with the task of selecting a new activity or activities that would address person-centered services in Kentucky. The committee discussed their top six issues regarding the new Supports for Community Living/Participant Directed Program with DDID staff. These included the required training for employees hired; the ID/DD definition that may affect eligibility; transportation, especially in rural areas; owning your own home; information on PDS consistency throughout the state; and better awareness of new services available through Participant Direction and how they can be utilized.

- **Goal:** Participants should be provided information on any new process as early as possible to avoid misunderstanding or lapse in services.

Activity: The Committee proposed hosting three regional events across the state to share information on the new SCL waiver and self-direction component; events which would feature a panel presentation by DBHDID staff. This task will be completed once the new SCL waiver is fully implemented.

Activity: Members of the Committee, which include self-advocates and family members, have shared information about new waiver services at various events held throughout the state including statewide self-advocacy conferences, regional educational workshops, regional parent/professional events, local organizational meetings, etc.

Activity: The PDS Committee drafted two informational briefs and an online survey. Approximately 3,900 people receive SCL services; however, only 150 have chosen to direct some or all of their services. In an effort to determine why few people have chosen to self-direct their services, the online survey was developed. This survey sought information about how information is shared and the advantages/disadvantages of services received. The survey was shared in meetings with self-advocacy groups, advocacy groups, and other organizations but due to a low response rate, the survey is being redrafted.

Activity: A goal of the PDS Committee is that every participant will have a user-friendly Participant Directed Program Manual. The manual will describe the program, services that can be participant directed, rights, etc. The Committee is currently reviewing templates for manual design.

Recommendations: The committee should discuss and describe new options for participant directed services (PDS) that would be detailed through PDS's user-friendly manual, when implemented.

Community Integration

- **Goal:** Beating Loneliness through Community Integration - Increase by 10% the overall percentage of people who report having friends who are not staff or family, as reported in the next NCI 12 month data cycle.

Activity: This committee held three community forums around the state to gather feedback from individuals, advocates, and providers regarding their perceptions of community integration and the barriers that they see and experience in maximizing the potential for full inclusion in the community. The attendees voiced difficulty in accessing services in the community including transportation. They spoke passionately about those they serve and their efforts in integrating those individuals into community activities, functions, employment, volunteerism, and family activities. In the coming year this group will continue to hold community forums. A presentation of the qualitative data gathered will be presented upon completion in.

STATISTICS

Status of programs providing supports to individuals with intellectual and/or developmental disabilities through FY 13.

ICF Average Annual Census FY 2008 through FY 2013

The number of people who reside in state Intermediate Care Facilities for individuals with Intellectual/Developmental Disabilities (ICF/IIDs) has decreased significantly with the implementation of the statewide transition process.

Facility	FY08	FY09	FY10	FY11	FY12	FY13
Oakwood	226	205	173	134	120	120
Hazelwood*	168	162	161	134	142	134
Bingham Gardens	32	34	32	28	24	23
Outwood	65	63	59	50	44	42
Total	491	464	425	346	330	319

*Hazelwood Center census includes the three 8-bed ICF community homes.

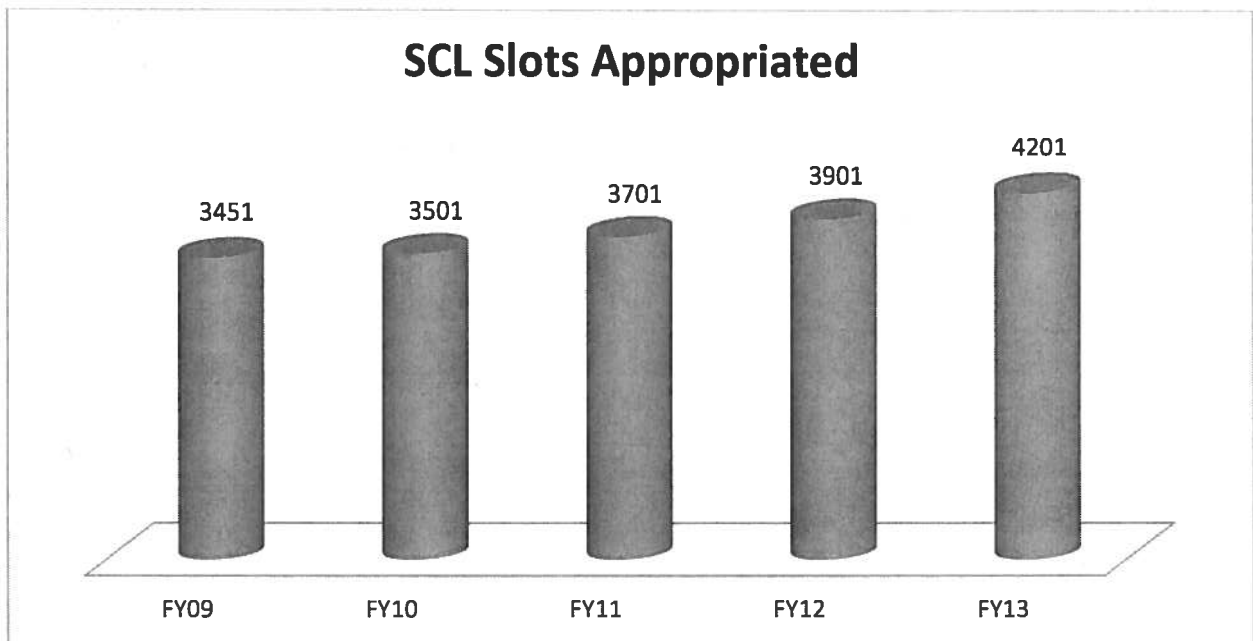
As part of the settlement agreement with the US Department of Justice, each of the state-owned ICFs is in the process of transforming into a Center of Excellence. These centers serve as a resource to individuals, families, and community providers by offering specialized supports and services that are not accessible in the community.

CMHC State General Fund Service Provision FY 2013

Based upon data reported by the Community Mental Health Centers, 3,470 people were supported with State General Fund dollars and received a total of 1,784,834 units of service.

- DBHDID staff work with CMHC staff on an ongoing basis to address issues related to data accuracy.
- CMHC adult DD crisis services were utilized 867 times.

SCL Waiver



SCL Slots	FY09	FY10	FY11	FY12	FY13
Total # Slots	3451	3501	3701	3901	4201
New Slots Funded	50	50	200	200	300

SCL Waiting List – as of June 30, 2013

Category on Waiting List			
Total	Emergency	Urgent	Future/Planning
	0	16	2080

2096			
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The efforts and success of this commission in obtaining 600 additional SCL waiver allocations allowed a 95% reduction in the number of individuals waiting in the urgent category in FY 2013. Of the 2096 people on the SCL waiting list as of June 30, 2013, only 3.5% reported receiving no services. Almost half (47.5%) receive services through the Michelle P Waiver.

Michelle P Waiver and Acquired Brain Injury Waivers

Reporting Methodology

Level of Care (LOC) - Numbers reported represent members having an active level of care during FY 2013.

Services - Numbers reported represent members having an active service plan during FY 2013.

Michelle P Waiver (MPW) Member Report Summary as of June 30, 2013

Members meeting Level of Care (LOC) without receiving services = 937

Members receiving 'Blended Services' (traditional and participant directed) = 1,630

Members receiving 'Traditional Services' = 2,695

Members receiving participant directed services only = 3,837

Total members 9,099

Members in MPW < 18 = 4,229

Members in MPW ≥ 18 = 4,870

Total members 9,099

Acquired Brain Injury (ABI) Waivers as of June 30, 2013 (all over age 18)

ABI Rehab Waiver

Members meeting Level of Care (LOC) without receiving services = 4

Members receiving 'Blended Services' (traditional and participant directed) = 3

Members receiving 'Traditional Services' = 145

Members receiving participant directed services only = 13

Total members 165

ABI Long Term Care Waiver

Members meeting Level of Care (LOC) without receiving services = 4

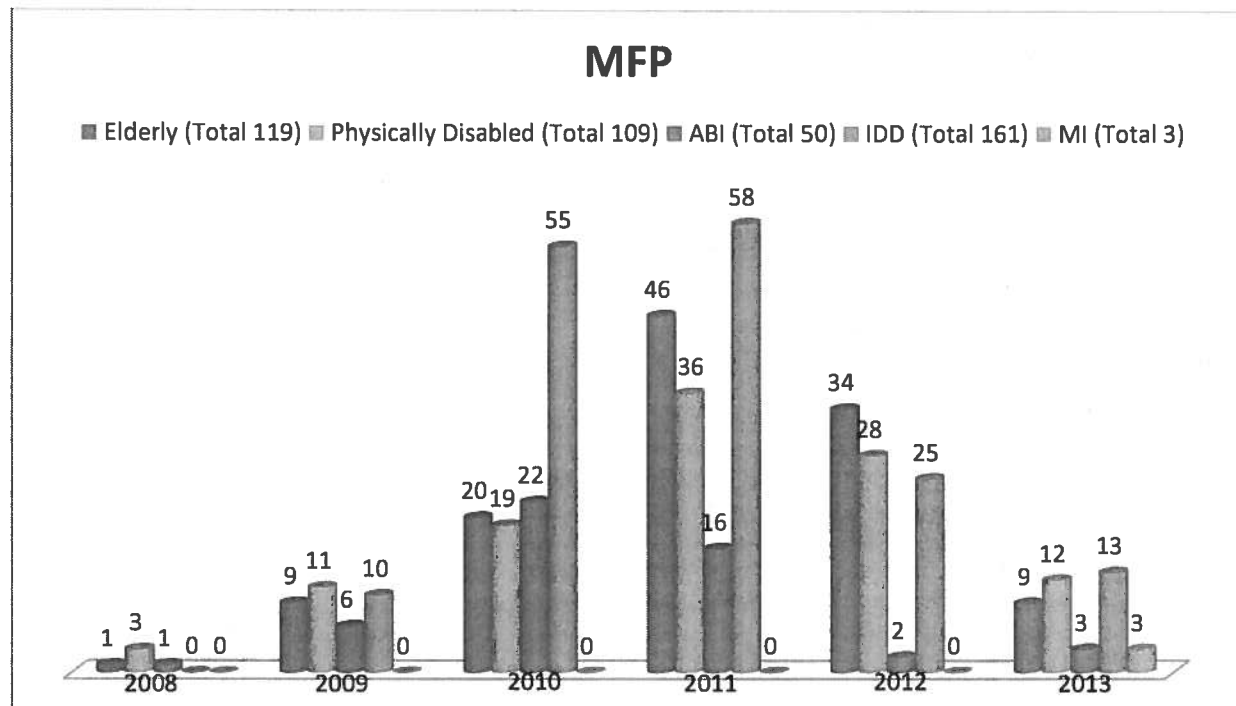
Members receiving 'Blended Services' (traditional and participant directed) = 16

Members receiving 'Traditional Services' = 170

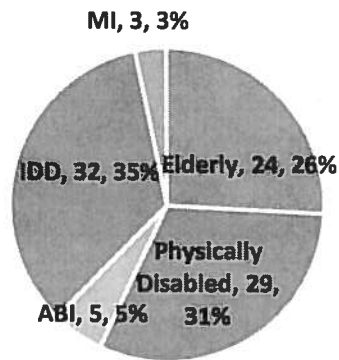
Members receiving participant directed services only = 35

Total members 225

Money Follows the Person (MFP)/Kentucky Transition



Year	Elderly	Physically Disabled	Acquired Brain Injury	Intellectual/Develop Disab	Mental Illness
2008	1	3	1	0	0
2009	9	11	6	10	0
2010	20	19	22	55	0
2011	46	36	16	58	0
2012	34	28	2	25	0
2013	9	12	3	13	3
Total	119	109	50	161	3
	26.9%	24.7%	11.3%	36.4%	.7%

MFP funding recipients as of May, 2013**CLOSING THOUGHTS**

Serving in an advisory capacity to the Governor and the General Assembly regarding the needs of persons with Intellectual and Developmental Disabilities has been a privilege for the Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities. Along with the Department for Behavior Health Developmental and Intellectual Disabilities, we look forward to meeting our goals to improve the quality of supports for citizens of Kentucky. The Commission Members extend their gratitude to the Governor and the General Assembly for their continued support.